

Grandparents Raising Grandchildren With Developmental Disabilities

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EXECUTIVE SUMMARY

Families continue to be the primary caregivers of children and adults with developmental disabilities, with over 60% of the disabled population living with families. At least one quarter of these family caregivers are over the age of 60 years (Fujiura, 1998). Increasingly these caregivers are grandparents who are caring for their grandchildren with disabilities. This paper examines 1) their demographics; 2) reasons for assuming this role; 3) their needs, concerns, and challenges; and 4) supportive networks. Additionally, it reviews supportive interventions for this population and implications for the aging network in designing and coordinating services as part of the National Family Caregiver Support Program.

Grandparents raising grandchildren with developmental disabilities have been a largely forgotten part of America's caregiver population. Yet, they likely comprise a large percentage of the grandparents raising grandchildren, as disability is more prevalent in families living in poverty, and in single parent households (Fujiura, 1998). Other factors associated with increased prevalence of disabilities are substance abuse and neglect, which contribute to grandparents taking over the caregiving role.

Grandparenting a child with disabilities includes challenges above and beyond those of other grandparents. Findings from the literature on grandparents not residing with their grandchild with disabilities, have indicated feelings of stress, depression and ambiguity concerning their roles as grandparents (Johnson, 1983; Mosala & Ikonen Mosala, 1985; Murphy & Della Corte, 1990, Vadasy et al., 1986). Research on mothers of children with disabilities has shown that having a child with a developmental disability does present more challenges, including emotional strain, financial hardships, career disruption, social isolation, and worry about the child's future. The literature also shows that many mothers cope well over the long-term as they become accustomed to the role (Seltzer & Krauss, 1994). However, it is not clear how grandparents who have not had life-long caregiving responsibility for the child cope with these caregiving demands. Janicki, McCallion, Grant-Griffin, & Kolomer's (2000) study found that most grandparents caring for grandchildren with developmental disabilities felt overwhelmed by the caregiving challenges. As with other grandparents in these roles they reported high rates of depression (57 percent). However, these grandparents also had to meet the demands of parenting a grandchild with complex behavioral or physical conditions. The impact on their lives included never being able to leave their grandchild alone or with someone else, experiencing less sleep, having physical challenges, and being physically assaulted. They reported a need for more supports and frustration with accessing services because of unclear guardianship and legal situations. A constant worry was a concern about maintaining caregiving as they aged and faced their own health declines.

Grandparents caring for grandchildren with disabilities have the challenges faced by other grandparents raising grandchildren, including difficulties in finding adequate housing, health care, and educational supports. However, they have additional challenges, such as finding housing that is accessible to persons with a disability. Also, children with developmental disabilities living with grandparents may be ineligible for an individual education plan. Though they have more contact with human service agencies than these other grandparent caregivers, grandparents caring for grandchildren with disabilities are generally low users of services (Force et al., 2000). Often, these grandparents lack information about such services, even though they

and their grandchildren may be eligible for them. This low contact does raise concern about the extent to which any planning occurs regarding the future needs of these grandchildren as they age out of the school system and as their grandparents can no longer maintain caregiving due to their frailty or death. Often grandparents caring for grandchildren with developmental disabilities have faced unresponsive service systems. Some of the difficulties include having to wait for long periods of time, lack of sufficient transportation to agency offices, and insufficient access to needed documentation (McCallion et al., 2000). An additional problem for these caregivers is the frustration of dealing with the fragmented service system.

There is little research on supportive interventions and programs specifically designed to meet the needs of grandparent caregivers of grandchildren with disabilities. Several psycho-education and support group programs have focused on grandparents who provide care but are not necessarily the primary caregivers (George, 1998; Vadasy et al., 1986). One comprehensive program specifically targeting the needs of grandparents caring for a child with developmental disabilities (McCallion et al., 2000) had the following components: (a) grandparent support group, (b) consumer-developed manual of locally based services, (c) peer support from other grandparents, and (d) active case management from the participating agencies. This intervention was successful in significantly reducing symptoms of depression and increasing grandparents' sense of empowerment and caregiving mastery.

With the recent passage of the Older Americans Act amendments of 2000 and the Administration on Aging National Family Caregiver Support Program, there is a recognition of the role of the aging network in supporting grandparents caring for children with intellectual and developmental disabilities. This review has indicated the need for programs targeting this group of grandparent caregivers, who face high caregiving demands and few resources to help them. In order to meet the need of these families, the following are some suggestions for the aging network and for the other networks which need to be involved in the process, including the developmental disabilities, child welfare, health care, and educational systems:

- Gather data on the number of grandparents that are primary caregivers for a grandchild with developmental disabilities and document the needs of the child and the family;
- Outreach to these families and connect them to needed services;
- Develop partnerships among agencies to address this issue;
- Fund and develop comprehensive intervention programs;
- Advocate for policy changes that include more supports for these grandparents; and
- Help grandparents develop plans for the future when they can no longer provide care.

INTRODUCTION

Families continue to be the primary caregivers of children and adults with developmental disabilities, with over 60% of the disabled population living with families. Developmental disabilities is defined as a condition that is: 1) attributable to mental or physical impairments (e.g., intellectual disabilities, cerebral palsy, epilepsy, neurological impairment or autism); 2) originates before age twenty two years; 3) is expected to continue life-long; and 4) constitutes a substantial impairment in at least three major functional activities (Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1994 (PL 103-230)). Of these family caregivers, over 25 percent are over the age of 60 years (Fujiura, 1998). Increasingly these caregivers are grandparents who are caring for their grandchildren with disabilities.

This paper profiles the caregiving experience of these grandparents. It reviews existing literature on: 1) their demographics; 2) reasons for assuming this role; 3) their needs, concerns, and challenges; and 4) supportive networks. Additionally it reviews promising practices for supporting this population and implications for the aging network in designing and coordinating services as part of the National Family Caregiver Support Program.

DEMOGRAPHIC TRENDS

Demographic trends indicate a growing increase in grandparent-headed families in every socioeconomic and ethnic group across America, the majority living in southern and in non-metropolitan areas (U.S. Bureau of Census, 1998). The percentage of children living in grandparent-headed families with or without parents has increased from 3.2 percent in 1970 to 5.6 percent in 1997. More than one in ten grandparents has raised a grandchild for at least six months and most of these grandchildren are less than six years old (Fuller-Thomson et al., 1997; U.S. Bureau of Census, 1998). Furthermore, 56 percent of custodial grandparents have provided care to a grandchild for at least three years and one in five custodial grandparents has taken care of their grandchild for more than ten years.

About 1.7 million (43.6 percent) of these children are living in non-Hispanic white grandparent-maintained families as compared to 1.4 million (35.9 percent) and 0.7 million (18 percent) of all children living in non-Hispanic African-American grandparent families and Hispanic grandparent maintained families respectively. Additionally, 8.3 percent of all grandparents (26 percent of African-American grandmothers and 7.3 percent of white grandmothers) live in households with their grandchildren (Szinovacz, 1998).

Nationally, slightly more than half of the grandparent caregivers are married (54 percent), more than three-quarters are women (77 percent) and 62 percent are non-Hispanic white. Being single, living in poverty, and being African-American substantially increases the odds of becoming a caregiver for one's grandchildren (Casper & Bryson, 1998; Chalfie, 1994; Fuller-Thomson et al., 1997; Harden et al., 1997).

Grandparents raising grandchildren with developmental disabilities have been a largely forgotten part of America's caregiver population. With improved medical care, dramatically increased life expectancy, and their growing presence in the community, this caregiver population should demand increased attention. Furthermore, developmental and other disabilities occur more

frequently among families living in poverty and in single parent household (Fujiura, 1998). Other factors associated with increased prevalence of disabilities are substance abuse and neglect, which contribute to grandparents taking over the caregiving role. Hence, one would expect a high prevalence of disabilities among families headed by grandparent caregivers (Force, Botsford, Pisano, & Holbert, 2000). Several studies have reported that grandchildren in grandparent headed households have high rates of asthma and other respiratory problems, weakened immune systems, physical disabilities, poor eating and sleeping patterns, and attention deficit disorders (Dowdell, 1995; Shore & Hayslip, 1994). Force and his colleagues report that up to 75% of families contacting the Grandparent Resource Center in New York City during a nine-month period were reported to have problems caring for a child with developmental disabilities. Yet, there has been little attention on this group of caregivers. One explanation for this neglect is that these grandparents are often viewed as an extension of foster care providers like siblings, rather than as a unique group of caregivers (Kolomer, 2000). In addition, the scant literature available is over-represented by grandparents of multicultural and inner city communities (McCallion et. al., 2000).

REASONS FOR BEING A CAREGIVER

Numerous studies looking into the reasons for grandparents assuming custodial care have reported that child maltreatment typically associated with substance abuse by either one or both parents as the primary reason for assuming custodial care (Dowdell, 1995; Jendrek, 1994; Pruchno, 1999). Other reasons for grandparents raising grandchildren include parental death (Pruchno, 1999; Schable et al., 1995) incarceration (Dowdell, 1995; Dressel & Barnhill, 1994; Gaudin & Sutphen, 1993; Kelley, 1993; Pruchno, 1999), mental illness (Dowdell, 1995; Kelley, 1993), and abandonment (Pruchno, 1999). The HIV/AIDS epidemic, a leading cause of death among the African-American population between the ages of 25-44 years, had contributed to an increase in grandparent caregiving among African-American children (Joslin & Harrison, 1998). Tied to the above factors is the impact of poverty, which is a vulnerability factor for both grandparent caregiving and for the prevalence of disability in the family.

There are very few empirical studies that have looked into the reasons for grandparents assuming the role of caregiver for grandchildren with developmental disabilities. In a study that involved 164 grandparents (80% African-American) in New York City, Janicki, McCallion, Grant-Griffin, & Kolomer (2000) found that substance abuse by the child's parent was the primary reason for grandparents taking the caregiver role, with preventing foster care placement as the second most prevalent reason. Other factors such as incarceration of the child's parents, parental death, and parents moving away also influenced the decision for grandparents to assume caregivers role. A majority of the grandparents reported that they would continue to provide care as long as their health permitted them.

CONCERNS AND CHALLENGES OF GRANDPARENTING

Studies in the gerontology literature have documented some of the responsibilities of grandmothers when they assume the role of primary caregiver for their grandchild, including being the primary contact person in case of emergency, signing reports cards, setting the rules, disciplining grandchildren, and attending parent teacher meetings and other school events (Pruchno, 1999). Studies of the long-term impact of caregiving by grandparents report high rates

of depression, poor self-rated health and/or frequent presence of chronic health problems—especially among grandmothers (Burton, 1992; Dowdell, 1995; Minkler & Roe, 1993; Minkler et al., 1997). Close to one-third of grandmother caregivers suffer from depression and over half have at least one limitation in activities of daily living (Fuller-Thomson & Minkler, 2000). Grandparent caregivers attribute stress to: decisions on long-term and permanent child care responsibilities; caregiver's physical ability to keep up with the school; social and physical activities of their grandchild; and presence of behavior problems of their grandchild (Burton, 1992; Pruchno, 1999).

Grandparent caregivers are 60 percent more likely to live in poverty than grandparents not raising grandchildren (Fuller-Thompson et al., 1997), with grandmother-headed households being the most impoverished. The research indicates that two-thirds of children living in grandmother-only headed households are living in poverty (Casper & Bryson, 1998). In a study by Burton (1992) over 78 percent of grandparent caregivers reported facing financial hardships while 52 percent reported not having the resources to meet the needs arising out of caregiving. In addition, grandparents have indicated having to quit their jobs and experiencing a decline in privacy and in time for themselves, for their spouse, and for social-recreational activities after taking on the primary caregiving role for their grandchildren (Burton, 1992; Jendrek, 1993; Minkler & Roe, 1993). Although caregiver grandparents also report positive experiences (Burton, 1992), the long term consequences of caregiving are overwhelming, with grandparents reporting lower well beings scores, lesser satisfaction with grandparent roles and poorer perception of grandparent-grandchild relationships as compared to non-caregiver grandparents (Minkler & Roe, 1993; Shore & Hayslip, 1994). Poor health and the high level of caregiving need of the grandchild also contribute to higher depression and stress (Burton, 1992).

Grandparenting a child with disabilities involves challenges above and beyond those of other grandparents who have taken the role of primary caregiver for their grandchild. Although caregiving for a grandchild with developmental disabilities is likely to be more demanding than caring for other children, there has been little research examining the long-term effects of the grandchild's disability on caregiver grandparents. Findings from the literature on grandparents not residing with their grandchild with disabilities, have indicated feelings of stress, depression and ambiguity concerning their roles as grandparents (Johnson, 1983; Mosala & Ikonen Mosala, 1985; Murphy & Della Corte, 1990; Vadasy et al., 1986). In a study conducted by Scherman et al. (1995), grandparents of children with spina bifida expressed concerns about their grandchild's medical condition, their ability to live independently and foster meaningful relationships in addition to the future care placements, inadequate financial resources, and the effects of the disabled grandchild on other grandchildren.

Research on mothers of children with disabilities has shown that having a child with a developmental disability does present more challenges, including emotional strain, financial hardships, career disruption, social isolation, and worry about the child's future. The literature also shows that many mothers cope progressively over the long-term as they become accustomed to the role (Seltzer, 2000). However, it is unclear how grandparents who have not had a life-long caregiving responsibility for the child cope with the caregiving demands of a child with a disability.

There is little information on the long-term impact of caregiving on the physical and mental status of grandparents caring for a child with developmental disabilities. In a study of grandparent caregivers in New York, Force et al. (2000) found that grandparent caregivers of grandchildren with developmental disabilities showed high rates of depression, but not significantly higher than that of other grandparent caregivers. However, the authors suggested that grandparents tended to underreport physical and mental health symptoms due to fear that the child may be taken away from their custody. In their study of 164 grandparents caring for a child with developmental disabilities in New York, of which nearly all were female (96 percent) and African-American (80 percent), Janicki and colleagues (2000) report that most of these families felt overwhelmed by the caregiving challenges. As with other grandparents in these roles they reported high rates of depression (57 percent). However, these grandparents also had to meet the demands of parenting a grandchild with complex behavioral or physical conditions. The impact on their lives included never being able to leave their grandchild alone or with someone else, experiencing less sleep, having physical challenges, and being physically assaulted. They were concerned about the caregiving demands presented by their grandchildren and worried that they would be perceived as inadequate in their roles. As in the previous study, they seemed to mask their day-to-day difficulties and under-report any physical or mental health problems lest they be perceived as incapable of providing support. Furthermore, grandparents reported negative attitudes from their peers regarding their caregiving competencies, adding to their feelings of isolation among their own peers. These families reported a need for more supports and frustration with accessing services because of unclear guardianship and legal situations. They experienced difficulties in accessing public assistance services and were frustrated with the time-consuming appointments. A constant worry was a concern about maintaining caregiving as they aged and faced their own health declines.

SUPPORT NETWORKS

Grandparent-headed families face a number of challenges in obtaining needed health care, financial and public assistance, legal supports, and adequate housing. Analysis of the calls over a nine month period to the toll-free hotline of the New York City Department of Aging's Grandparent Resource Center from grandparents of children with disabilities indicated five major areas of unmet support needs: 1) financial, 2) guardianship, 3) respite care, 4) emotional support, and 5) problems interacting with multiple social service systems, including accessing health care, educational supports and housing (McCallion et al., 2000).

Access to health care is perhaps one of the most important challenges faced by grandparent caregivers. Often these caregivers delay or fail to seek health services for their own health (Minkler & Roe, 1993). Furthermore, many insurance companies disallow their grandchildren as dependents on their policies unless the grandparent has legal custody. One in three children in grandparent-headed households were without insurance as compared to one in seven in the overall child population in 1996 (Casper & Bryson, 1998). Physicians in emergency rooms may also be less likely to provide services without a signed legal guardian consent.

As noted earlier, grandparent headed families have high rates of poverty, which is further exacerbated by the costs of caregiving for their grandchildren (Minkler & Roe, 1993). Prior to the welfare reform that occurred in 1996, the Aid to Families with Dependent Children (AFDC) program was their primary course of financial assistance. The new program, Temporary

Assistance to Needy Families (TANF), could negatively impact the caregiver grandparent's ability to receive benefits for oneself or the child due to its work requirements, time limits (up to five years) and other restrictions (Mullen & Einhorn, 2000). If the grandparent limits the TANF funds to "child-only" (versus for the caregiver) then some of the work and time limit restrictions are lifted but the funds provided are usually lower. In 20 states, stipended guardianships are available for relatives who were in the formal foster care system and then exited it. These stipends are higher than those of TANF but lower than the foster care stipends. However, grandparent caregivers report considerable difficulty in obtaining support for which they are eligible and experience delay, red tape and other difficulties in trying to access the needed financial assistance (Burnette, 1997; Generation United, 1998). Grandparents caring for grandchildren with developmental disabilities are more likely than other grandparent caregivers to use food stamps and to use child care benefits (Force et al., 2000). However, the unique concerns of grandparents caring for grandchildren with disabilities has rarely been considered in the discussions regarding welfare reform.

Access to adequate and affordable housing is a major concern for many grandparents. For low-income caregivers, purchasing or renting housing with sufficient space and safety for themselves and their grandchildren continues to be a major challenge. The existing federal, state, and local housing policies have not addressed the special needs of the grandparent caregiver. Grandparents in senior housing or other public housing could face eviction should their grandchildren live with them. Grandparents caring for grandchildren with disabilities have the additional challenges of finding housing that is accessible to persons with a disability.

Grandparent-headed households also face challenging legal issues. While legalizing the care arrangement would enable the grandparents to access services and supports for their grandchild, many caregivers are reluctant to do so. Grandparents who enter into formal kinship are eligible for foster care payments, but the hopes of eventual reunification, fear of antagonizing other family members and the costs involved in legal proceedings often make caregiver grandparents reluctant to formalize custody (Generations United, 2001; Minkler, 1999). Opting for more informal arrangements limits their rights in dealing with school, health and other social service agencies, as proof of legal authority often is a prerequisite for providing services. In Janicki et al.'s (2000) study of grandparents caring for grandchildren with developmental disabilities in New York, 37 percent were court-appointed guardians, 20 percent had temporary court custody, 14 percent were in kinship foster care, 14 percent were in informal care, and only 9 percent were adopted by the grandparent.

School policies are most often geared towards nuclear families, resulting in numerous obstacles for grandparent led families. These obstacles include inability to enroll without proof of legal guardianship, ineligibility for transportation to another school district, and additional fees for out-of-district enrollment. Children with developmental disabilities living with grandparents may also be ineligible for an individual education plan. In their study comparing grandparents caring for grandchildren with developmental disabilities with those caring for grandchildren without developmental disabilities, Force et al. (2000) found that the families with a disabled grandchild had a greater need for help with schools and a greater need for transportation. They also were more likely to have contacts with the child's schools, family court, local developmental disabilities services offices, and child welfare agencies. Though they had more contact with human service agencies than other grandparent caregivers, these grandparents were generally

low users of services. For example only 10 percent had contacts with the developmental disabilities service network and only 7 percent had contact with the aging network. Often these grandparents lack information about such services, even though they and their grandchildren may be eligible for them. This low contact does raise concern about the extent to which any planning occurs regarding the future needs of these grandchildren as they age out of the school system and as their grandparents can no longer maintain caregiving due to their frailty or death.

Often grandparents caring for grandchildren with developmental disabilities have faced unresponsive service systems. They have reported being denied benefits such as social security-disability and Medicaid even when they fit the criteria for eligibility. Some of the difficulties include having to wait for long periods of time, lack of sufficient transportation to agency offices, and insufficient access to needed documentation (McCallion et al., 2000). An additional problem for these caregivers is the frustration of dealing with the fragmented service system. For example being a client in one system (e.g., child and family services) sometimes precludes obtaining services from the disability network.

PROMISING PRACTICES IN SUPPORTIVE INTERVENTIONS

The last two decades have witnessed the growth of a wide array of supportive interventions in response to the increasing number of grandparent caregivers and the challenges faced in these households (Minkler, 1999). These include support groups, phone and Internet resources, resource centers, and public policy advocacy groups. The most common form of intervention is support groups, which can vary from informal meetings in grandparents' homes to a therapeutic support group providing childcare, transportation, and counseling (Minkler, 2001). With the rise of the Internet, many families receive support from other families and information from web sites and chat rooms.

There is little research on supportive interventions and programs specifically designed to meet the needs of grandparent caregivers of grandchildren with disabilities. Several programs have focused on grandparents who provide care but are not necessarily the primary caregivers. One of the earliest programs described in the literature is the Supporting Extended Family Members (SEFAM) project in Seattle (Vadasy et al., 1986). The project conducted regular workshops wherein professionals provided information sought by grandparents. Also, the workshops provided a forum for grandparents to share their experiences. George (1988) described a similar program wherein information and support were provided to grandparents. One of the only comprehensive programs specifically targeting the needs of grandparents was implemented in New York with 97 families (McCallion et al., 2000). The project had the following components: (a) grandparent support group, (b) consumer-developed manual of locally based services, (c) peer support from other grandparents; and (d) active case management from the participating agencies. This intervention was successful in significantly reducing symptoms of depression and increasing grandparents' senses of empowerment and caregiving mastery.

In terms of the broader grandparent caregiver population, two national level resource centers that can provide information and advocacy include the American Association for Retired Persons' (AARP) Grandparent Information Center and Generations United. The Grandparent Information Centers provide information about services and programs specifically for grandparent-headed households. Generations United is a national membership organization that focuses on promoting

intergenerational strategies, programs, and policies. With the inclusion of grandparent-headed households in the National Family Caregiver Support Program (NFCSP), the aging network may want to consider allocating a certain percentage of funds for the establishment of grandparent caregiver resource centers.

One of the most exciting and innovative approaches to meeting the needs of custodial grandparents that is being replicated in eight other cities is the GrandFamilies House in Boston, a 26 unit complex of two, three and four bedroom apartments (Gottlieb & Silverstein, 2000; Kauffman & Goldberg-Glen, 2000). The barrier-free complex was created by two local non-profit agencies using both public and private financing. Physical accommodations to aid both toddlers and grandparents, on site programs, and a task force to promote advocacy on behalf of grandparent headed households are among the features offered.

In addition, there are several national, state, and local coalitions that have formed specifically to advocate for policy changes regarding programs pertaining to grandparent caregivers. Two examples are the Wisconsin National Coalition of Grandparents (NCOG) and the California Grandparents as Parents (GAP). These groups liaison with legislators and the mass media and advocate for new laws or changes in existing laws to help support grandparent caregivers.

IMPLICATIONS FOR THE AGING NETWORK

With the recent passage of the Older American Act amendments of 2000 and the Administration on Aging National Family Caregiver Support Program, there is a recognition of the role of the aging network in supporting grandparents caring for children with intellectual and developmental disabilities. This review of the literature and programs indicated the need for programs targeting this group of grandparent caregivers, who face high caregiving demands and few resources to help them. In order to meet the need of these families, the following are some suggestions for the aging network and for the other networks which need to be involved in the process, including the developmental disabilities, child welfare, health care, and educational systems.

- **Gather data on the number of grandparents that are primary caregivers for a grandchild with developmental disabilities and document the needs of the child and the family.** We know that the rate of disability and of poverty is high in this group. Hence, we expect that a large proportion of grandparent caregivers is caring for a child with disabilities, yet we have little data on their needs.
- **Outreach to these families and connect them to needed services.** Many of these families are not connected with services that they may be eligible for and need. Generally, they have low awareness of the programs that that they may be eligible for such as Medicaid eligibility or housing services.
- **Develop interagency partnerships.** There is much fragmentation between the different networks and these families often fall between the cracks, where eligibility for one network precludes eligibility for the other one. The national grandparent caregiver advocacy efforts need to ensure inclusion of the needs of grandparents caring for children with developmental disabilities. This can be done through organizing meetings of the child welfare, disabilities, and aging networks to discuss issues and work on joint initiatives.

- **Fund and develop comprehensive intervention programs.** These programs could include psycho-educational support groups; networking among grandparents; support brokerage in obtaining financial subsidies, educational, health care, and housing support; legal help in obtaining permanency planning or foster care designation; and assistive technology to help both the aging grandparent and the child with disabilities.
- **Advocate for policy changes that include more supports for this caregiver population.** There is a need for changes in state-wide policies that allow informal grandparent caregivers to have rights to speak up for their children in the school system and that enable them to access resources for themselves and their grandchildren. Furthermore, there is a need for development of better public and private housing supports and improved access to good health care.
- **Help grandparents develop plans for the future when they can no longer provide care.** Though families often live from day to day rather than thinking about the longer-term future, these families need to plan for transitions into other residential placements as the child becomes an adult and the grandparent can no longer assume the caregiving function (i.e., due to frailty or death).

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Tamar Heller, Ph.D., Professor of Human Development and Public Health, is Interim Head of the Department of Disability and Human Development, University of Illinois at Chicago. She also directs the Rehabilitation Research and Training Center (RRTC) on Aging with Developmental Disabilities (funded by the National Institute on Disability and Rehabilitation Research, grant # H133B980046) and projects on family support and health promotion interventions for individuals with developmental disabilities and their families. Dr. Heller has written over 100 publications; including co-editing two books, *Health of Women with Intellectual Disabilities* and *Older Adults with Developmental Disabilities: Optimizing Choice and Change*, and two special journal issues of *Family Relations* and of *Technology and Disability*. Previously, Dr. Heller directed a Family Studies and Services Program, which included an interdisciplinary diagnostic clinic serving nearly 1000 families per year from the inner city, a family support program and studies on lifespan family support. Dr. Heller has served as president of the gerontology division of the American Association on Mental Retardation (AAMR) and has served on boards of AAMR, the European Course on Mental Retardation, and several leading national and international journals on disability issues.

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RECOMMENDED RESOURCES

Aging Network

AARP Grandparent Information Center

601 E Street, NW
Washington, DC 20049
(202) 434-2296
gic@aarp.org
www.aarp.org

Relatives as Parents Program (RAPP)

Brookdale Foundation Group
125 East 56th Street
New York, NY 10022
(212) 308-7355
www.ewol.com/brookdale

Generations United

122 C Street, NW, Suite 820
(202) 638-1263
fax: (202) 638-7555
gu@gu.org
www.gu.org

Administration on Aging

330 Independence Avenue, SW
Washington, DC 20201
(202) 619-7501 (National Aging Information Center)
(800) 677-1116 (Eldercare Locator)
www.aoa.gov

Grandparent Caregiver Law Center

Brookdale Center on Aging
1114 Avenue of the Americas
New York, NY 10036
(646) 366-1000
www.brookdale.org

National Coalition of Grandparents (NCOG)

137 Larkin St.
Madison, WI 53705
(608) 238-8751

Developmental Disabilities Network

The ARC of the United States, Headquarters (ARC)

1010 Wayne Avenue, Suite 650
Silver Spring, MD 20910
301/565-3842
301/565-3843 fax
info@thearc.org
www.thearc.org

Association of University Centers on Disability (AUCD)

8630 Fenton Street, Suite 410
Silver Spring, MD 20910
301/588-8252
301/588-2842 fax
gjesien@aucd.org
www.aucd.org

National Association of Developmental Disability Councils (NADDC)

1234 Massachusetts Ave, NW Suite 103
Washington, DC 20005
202/347-1234
202/347-4023 fax
naddc@naddc.org
www.naddc.org

American Association on Mental Retardation (AAMR)

444 North Capitol Street, NW Suite 846
Washington, D.C. 20001-1512
202/387-1968 or 800/424-3688
202/387-2193 fax
dcroser@aamr.org
<http://www.aamr.org/>

National Association of State Directors of Developmental Disabilities (NASDDDS)

113 Oronoco Street
Alexandria, VA 22314
703/683-4202
703/684-1395 fax
rgettings@nasdds.org
<http://www.nasdds.org/>

Centers Specializing in Aging and Developmental Disabilities

Center on Intellectual Disabilities

Ringel Institute – R1208
State University of New York—Albany
Albany, NY 12222
518-442-4097
mcclion@csc.albany.edu

**Rehabilitation Research and Training Center on Aging with Developmental Disabilities
(RRTCADD)**

Department of Disability and Human Development, (MC 626)
University of Illinois at Chicago
1640 West Roosevelt Road
Chicago, Illinois 60608-6904
312/413-1520
312/413-0453 tty
312/996-6942 fax
theller@uic.edu
<http://www.uic.edu/orgs/rrtcamr/>